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Inequalities in access to health and social care among adults with multiple sclerosis: A scoping review of the literature

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All authors declare that they have no conflict of interest in submitting this manuscript.

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ABSTRACT (300 words unstructured)

Variations in access to health care are known to contribute to differences in life expectancy, morbidity and health-related quality-of-life across population subgroups. We undertook a scoping review to identify what is known about in-country variations in access to services for adults with multiple sclerosis and to identify gaps in the literature to inform future research and national policies. We searched MEDLINE, CINAHL, EMBASE, PSYCHINFO, SocINDEX and Social Science Abstracts from inception to end of December 2016 for quantitative studies which had investigated differences in access to prevention services, healthcare services, treatments and social care between inequality groups, defined using the PROGRESS-PLUS framework. A total of 4959 unique abstracts yielded 36 papers which met our eligibility criteria. Only 3 studies were cohort studies and only 4 were population-based; most were from the United States (n=27). There were 6 studies on access to MS focused care and 6 on access to Disease Modifying treatments. There were 3 studies on access to prevention/lifestyle programmes and none on access to welfare services or information support. There were no papers examining inequalities in access for 'vulnerable' groups, such as, those with learning disability. In the available studies, there was evidence of inequalities in access to services with a trend for worse access among men, older age groups, those from lower socio-economic groups or the least educated, non-caucasians, those with mental health problems and those from rural areas. In the studies on access to disease modifying treatments, older age and lower socioeconomic status were consistently associated with a lower rate of uptake, while race and gender were not. Inequalities or disparities in access to all levels of services and treatments will need to be addressed through a strategic research agenda with an emphasis on population-based studies and development and evaluation of interventions to reduce inequality.

INTRODUCTION

Variations in access to health care are known to contribute to differences in life expectancy, morbidity and health-related quality-of-life across population subgroups [1-4]. When these variations are avoidable they contribute to inequalities or disparities in health experience [5] and have led to international and national strategies to reduce gaps in service provision, particularly, when there is evidence of lack of access to proven effective interventions or clinical variations in care [6-8].

The Multiple Sclerosis Atlas has demonstrated gross international differences in mortality in multiple sclerosis and access to disease modifying treatments [9]. However, studies also suggest variations within countries, with some evidence that place of residence and sociodemographic characteristics (e.g., age, gender and ethnicity) have an influence on patient outcome [10-12]. There is also concern about variations in access to disease modifying treatments for some patient subgroups, which might be, in part, secondary to how health services are organised [13,14]. In chronic conditions like multiple sclerosis (MS), it is also important to consider inequalities in access to services and treatments which reduce morbidity across the care pathway, from secondary prevention to rehabilitation and social care [15]. The complex needs of many patients with MS require the input of many other services, such as physiotherapy, occupational therapy and mental health services, as these treatments/therapies have been shown to reduce morbidity in MS [16-18]. Independence and participation may be maintained through social support, personal support and housing adaptations, and the employment consequences of an MS diagnosis through vocational rehabilitation [19]. More recently, there has been a greater focus on improving well-being through promoting healthy lifestyles among adults with multiple sclerosis, because of evidence that increased physical activity helps to maintain physical functioning and improve mental health in MS patients [20] and because smoking may raise the risk of disease progression [21]. Therefore, variations in access to lifestyle and prevention programmes is also important.

We undertook a scoping review of the literature to identify what is known about in-country variations in access to services for adults with MS and to identify gaps in the literature to inform future research and national policies. A scoping review uses systematic methods to identify the literature but addresses a broader question than a systematic review. As such, it is less concerned with the reporting quality of the papers or meta-analysis. In this scoping review, we identified and reviewed studies which used a quantitative methodology to investigate intra-national (in-country) variations in access across the care pathway and health systems of different inequality groups among populations of adult MS patients.

METHODS

Although this study was not focused on the effectiveness of interventions to reduce inequity, we used the Joanna Briggs Institute guidance on scoping reviews [22] and the Cochrane and Campbell Equity methods group checklist [23] to guide the

development of the study protocol, study implementation and presentation of findings. This study was funded by Salford Royal NHS Hospitals Foundation Trust.

Definition of exposures (Inequality groups)

We used the PROGRESS-PLUS framework for determining inequality groups in this review [24]. These were used to guide terms in the search strategy and to stratify studies in the analysis. In this framework the PROGRESS inequality groups (place of residence, race/ethnicity/culture/language, occupation/employment status, gender/sex, religion, education, socio-economic status, and social capital) were supplemented by 'PLUS' inequality groups related to personal characteristics pertinent to MS patients: age, disability (physical +/or cognitive), disease type, mental health conditions, and other 'vulnerable groups', e.g., learning difficulties, travelers, migrants. The 'PLUS' groups were chosen based on the potential for barriers to access of services and/or treatments following discussion within the review team, which consisted of clinicians and public health professionals. When considering social capital, we took a broad and inclusive approach to its definition and included all aspects of social networks and social cohesion under this umbrella term [25]. We also included a broad range of indicators of socioeconomic status, e.g, deprivation indices, income.

Definition of outcomes (programmes/services/treatments)

À priori, we broadly categorised the programmes/services/treatments and, post-hoc, agreed subcategories for presentation when studies were found. The categories (and subcategories) included: prevention programmes (subcategories: primary and secondary prevention), diagnostic investigations, medical care (subcategories: medication general, disease modifying treatments, general health care, neurology services, MS specific services, health provider systems e.g., health maintenance organisation), mental health services, rehabilitation services, social and welfare services (personal support, housing, assisted devices or assisted living) and information support.

Eligibility criteria

We included studies with a quantitative research design from any country and healthcare setting if they compared inequality MS groups as to uptake of, or access to programmes, services or treatments across the prevention/care/support pathway. Participants could have any type or stage of MS and be at any time following diagnosis. As the focus was on adult MS patients, we excluded any study in which more than 5% of the population was under 16 years of age. We also excluded studies comparing MS patients with the general population or with other patient groups, studies investigating uptake of alternative or complementary therapies, those that focused on uptake of lifestyles rather than the services which promote lifestyle

modification, those investigating DMT adherence rather than prescription and studies where the outcome was perceived or reported need, rather than comparative need.

Search strategy

We searched MEDLINE, CINAHL, EMBASE, PSYCHINFO, SocINDEX and Social Science Abstracts from inception to end of December 2016 using the key terms for multiple sclerosis as recommended by the Cochrane Multiple Sclerosis and Rare Diseases Review Group [26] and search terms for inequalities/disparities and the inequality groups, adapted as appropriate for the different databases. The search was limited to English Language articles. The full search strategy for MEDLINE (EBSCO) is included in supplementary materials (supplementary table 1). The titles and abstracts were screened by teams of two authors independently and any conflicts resolved by a third reviewer.

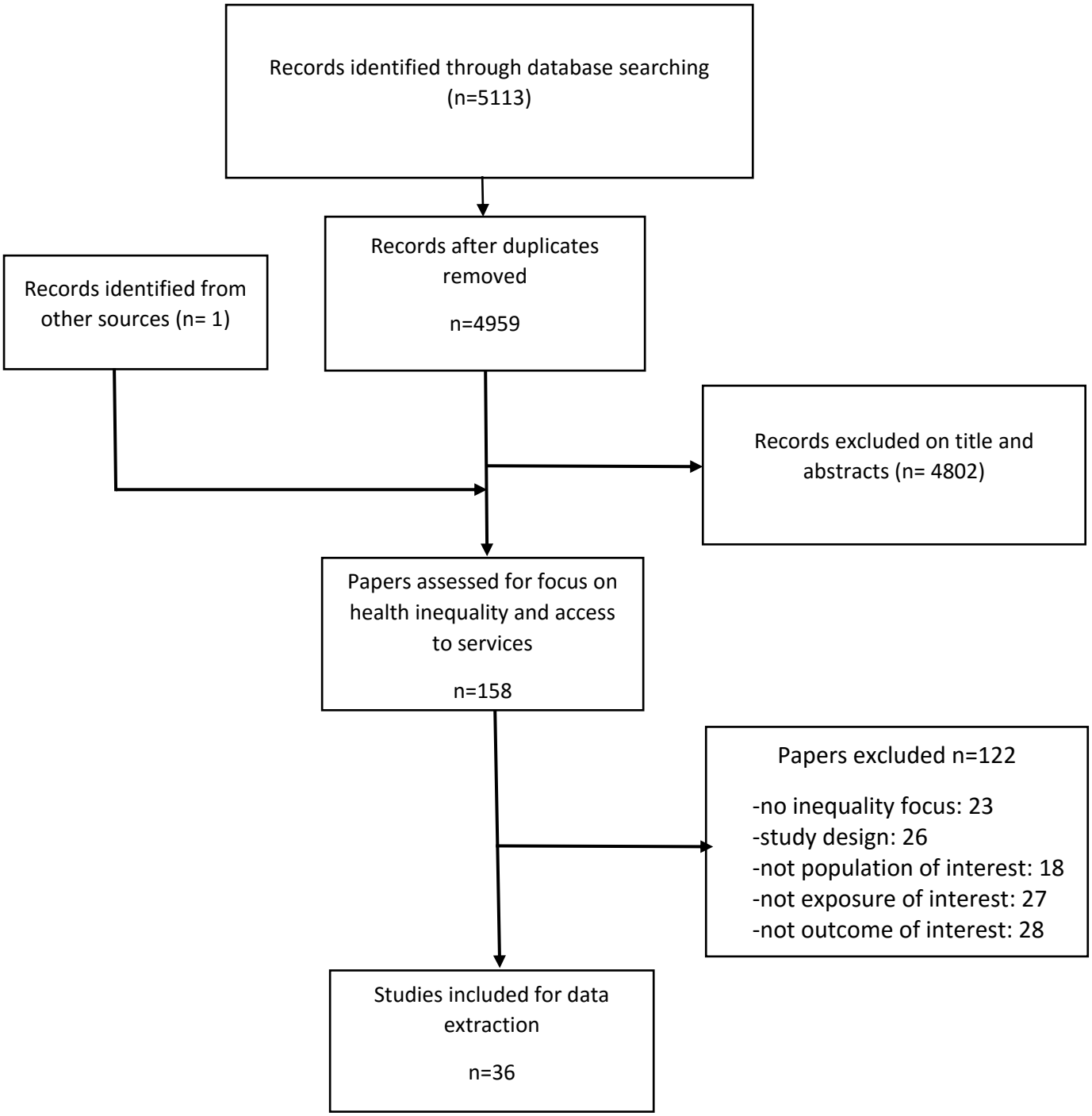
Data retrieval, extraction and analysis

Full text papers for all potentially eligible studies identified by the search, and when there was insufficient detail in the title/abstract to determine eligibility, were retrieved and screened for inclusion by two researchers, with a third reviewer resolving any conflicts. Data was extracted for each of the identified studies using a specially designed proforma. Data was extracted on the study design, country and setting, definition of MS, sample size, population characteristics, setting, data source, exposures (PROGRESS-PLUS categories), outcomes (uptake/access) and key findings for each exposure/outcome relationship reported. Data was extracted by one researcher and all data was checked by a second researcher, with conflicts being resolved by discussion. The dataset was synthesised narratively after discussion with the full review team.

RESULTS

A total of 4959 unique abstracts were identified from the databases following automatic removal of duplicates. This yielded 157 full text papers for eligibility screening and a further paper was identified from other sources [15]. A total of 36 papers were deemed eligible for further analysis [15, 27-61]. Reasons for exclusion for the other 122 papers included: a lack of focus on inequality (n = 23); non-eligible study design (n= 26); non-eligible study population (n=18); exposures inconsistent with the PROGRESS-PLUS framework (n=27) or lack of data on access to a service or treatment (n=28). Figure 1 shows the flow diagram of search results.

Figure 1: Flow chart of search



The full characteristics of the 36 studies is shown in supplementary table 2. Only 3 studies were cohort studies [28, 47, 55] and only 4 were population-based [46, 47, 52, 58]. The data source for 12 of the 36 was in full, or in part, from the members of National Multiple Sclerosis Society [32, 33, 36, 37, 41, 42, 43, 48, 49, 53, 54, 56] and for 4 studies the North American Research Committee on Multiple Sclerosis (NARCOMS) register [30, 44, 45, 56]. There were also 4 studies which used the Minimum Data Set (MDS) for Medicare/Medicaid certified Nursing Homes (two of which used the same sample) [29, 31, 34, 35] and 3 which drew on a single survey (‘’Aging With MS: Unmet Needs in the Great Lakes Region" survey) [38, 39, 40]. The

studies were published between 2000 and 2016 with 10 studies published since 2010 [30, 38, 39, 46, 47, 51, 53, 55, 56, 61]. Most of the studies were undertaken in the US (n=27) and all studies were undertaken in North America or Western Europe.

Figure 2 and table 1 show the numbers of studies focusing on the different access outcome categories and subcategories. There were 10 unique studies on access to medical services, of which, six studies were on access to MS focused care. Eight unique studies focused on access to medications, of which, 6 were on access to Disease Modifying treatments. A similar number of papers were on access to mental health services (n=7), rehabilitation (n=8), and social support/care (n=7). There were a few studies on diagnostic services (n=2), access to prevention/lifestyle programmes (n=3) and on housing adaptions or aids (n=4), but no studies on access to welfare services or information support. All three studies about inequalities in access to health provider systems were from the United States.

Figure 2: Number of papers by access subcategory

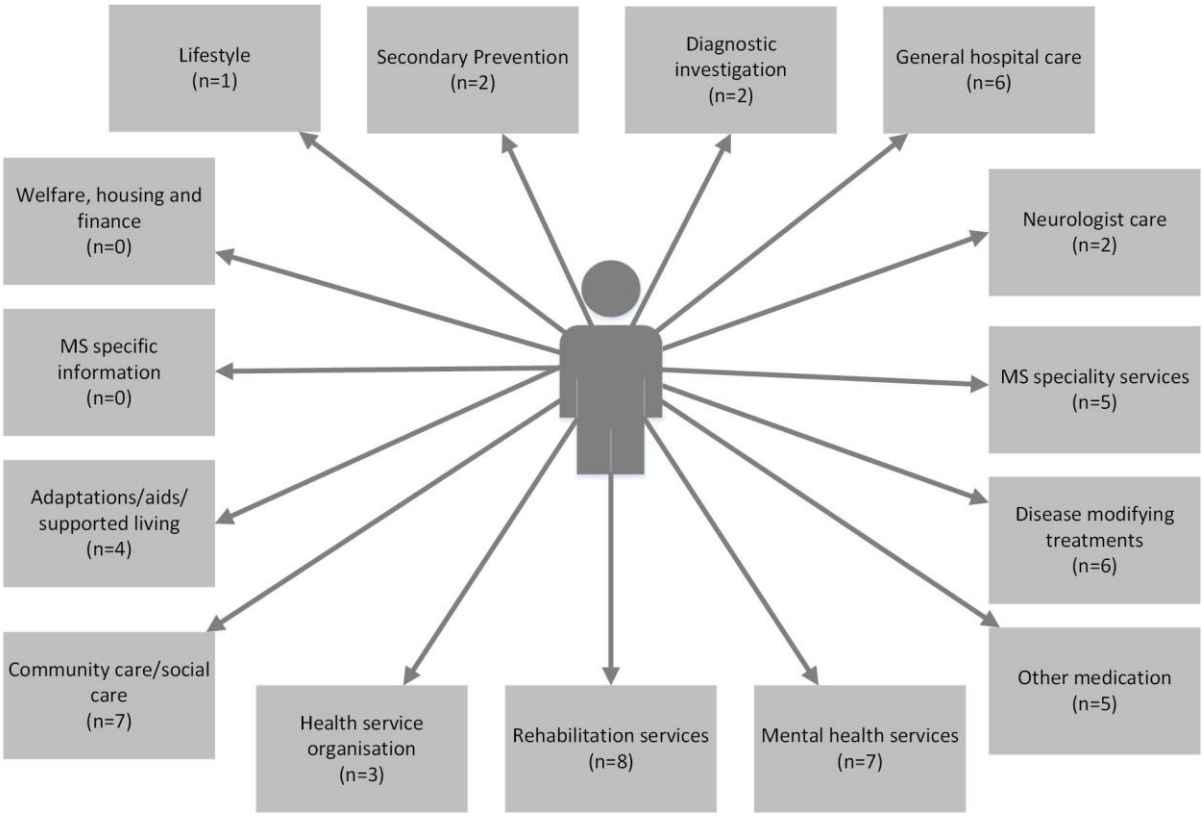


Table 1 summary of findings here (see separate file)

The effect of gender was examined across all access subcategories for which there were studies, and disability and socioeconomic status across all but one. Gender (n=25), age (n=21) and disability (n=18) were most frequently included as exposure factors. In contrast, mental health status (n=9), occupation, i.e., employment status,

(n=9), and disease type (n=7) were less frequently examined. Given the setting of most of the papers, the 15 studies about race mainly focused on differences between Caucasian, African American and Hispanic populations. Those on place (n= 13) compared urban and rural populations and all the papers categorised under social capital (n= 14) were on marital status or living arrangements. There were no papers examining 'vulnerable' groups or religion as factors affecting access to services/treatments.

The findings for each access category is shown in table 1. There was evidence of inequalities in access to services, but the relationship was not consistent across access subcategories. Broadly, there was a trend for worse access among men, older age groups, those from lower socio-economic groups or the least educated, non-caucasians, those with mental health problems and those from rural areas. However these findings were not universal, for example, women were less likely than men to see a urologist or have a powered wheelchair, and younger patients were less likely to be in receipt of personal assistance. In the studies on access to disease modifying treatments, older age and lower socioeconomic status were consistently associated with a lower rate of uptake, while race and gender were not. The relationship between severity of disability and levels of access across the care pathway was complex; with evidence of worse access to primary prevention and neurology services, no evidence of access issues to MS specific care and better access to rehabilitation, social care and assisted living.

DISCUSSION

In the limited number of studies identified, the findings of this scoping review support the existence of inequality, or disparity, in access to services among MS subpopulations within countries. The subpopulations experiencing inequality are similar to those experiencing access or uptake issues in other conditions. For example, in cancer screening men, minority ethnic groups and those from more deprived areas have lower rates of bowel screening [62]; older adults are less likely to receive proven effective treatments [63]; and rurality has been associated with lower access to specialist services [64]. However, this review also suggests that interpreting variations in access rates as an inequality or disparity is complex. There was some evidence that inequalities may be context specific. For example, women rather than men were less likely to be referred to a urologist. Urinary symptoms are very common in multiple sclerosis, but one study suggested that only two thirds of patients are asked about these symptoms by their clinician [65]. Gender disparity in referral to urologists has also been observed in general populations with haematuria and voiding difficulties, with women less likely to be referred and more likely to be treated for urinary tract infections [66,67]. Depending on the population subgroup, a higher or a lower uptake rate might be interpreted as an inequality for the same service. For example, in the study by Marrie [46], access to ICU was lower among those living in rural areas, which might suggest that because of the distance from specialist services those in rural areas could not obtain necessary management. However, access to intensive care units (ICU) was higher among men and older

patients. This could be interpreted as women and younger patients being less likely to benefit from necessary care; but equally could be interpreted that men and older patients are less likely to receive appropriate care to prevent overwhelming infections. Similarly, a lower rate of access to lifestyle interventions among those who are more disabled may be an inequality if they can benefit from these services; whereas a lower rate of access to home adaptations among those who are less disabled may not be an inequality, if they do not need such aids. These examples highlight the need for research to understand the reasons for differences between population subgroups: whilst some of these are likely to be similar to those experienced by adults with other co-morbidities [68], some are likely to be disease specific. Such research will also facilitate the development of strategies to reduce important variations.

Further difficulties in interpretation were introduced by the study designs. Few studies used a cohort design and therefore in most studies both exposure and outcome were measured at the same time. While this may not affect some exposures (such as gender), the interpretation of the direction of effect can be more problematic for exposures such as mental health or disability. So for example, in the study by Buchanan et al, nursing residents who were depressed were less likely to have occupational therapy (OT) [29]. As this was a cross-sectional study, it was unclear whether they had less OT because they were depressed, or not having OT made them depressed. Furthermore, there were other concerns about the quality of these studies: not all studies undertook a multivariate analysis to assess whether the exposures were independent risk factors. Few studies were population-based and many relied on members of MS societies: these groups might be less likely to include those from lower socio-economic groups, the less educated and minority groups [42, 43]. Finally, the generalisability of the findings may be limited because the majority were undertaken in US and all within western developed countries. Even then, the organisation and funding of health and social care systems in the US and the geography and racial breakdown are substantially different to that of, for example, the United Kingdom, where only 3 studies have been undertaken [15, 51, 52].

There were a relatively high number of studies investigating access to disease modifying treatments. This is perhaps unsurprising, given the controversies around funding of these effective but expensive drugs; particularly when they first came to market [51]. More recent studies suggest that in addition to concerns about socioeconomic disadvantage having an impact on access to first line Disease Modifying Treatments (DMTs), there still remain concern about access of patients from lower socioeconomic groups to second line treatments [69]. There were very few studies about prevention programmes, which might reflect the relative recency of the interest in lifestyle interventions to promote well-being in MS populations. Nevertheless, promotion of physical activity, safe alcohol consumption and smoking cessation are incorporated into some national guidelines for MS care [70], and further work on access to these interventions overall and across inequality groups is warranted. It is perhaps more surprising that there were no studies on access to vocational rehabilitation services, and few on the impact of unemployment on access

to services, given the considerable research on the difficulties encountered by adults with MS within the workplace and the detrimental impact of unemployment on their well-being [71, 72]. We also found no studies about access to informational support. There is increasing interest in developing self-management programmes including digital technology for patients. While such programmes are important to promote well-being and patient engagement [13], there is the potential for introducing further health inequalities, as access to and use of the internet or mobile devices differs across socioeconomic and racial groups [73].

As well as the difficulties in interpretation, there were other limitations to our scoping review. Because of resource limitations, only studies in the English language were included. This may in part account for the observation that there were relatively few countries included among the eligible studies. We specifically excluded studies which focused only on perceived or expressed needs, as these are subjective. Studies reporting objectively measured needs were included, but perceived or expressed needs may under represent genuine inequalities as they may represent wants, although studies have shown that these can vary across inequality group [74]. We did not include qualitative studies as the objective was to compare across inequality groups, but these types of studies would give greater depth of understanding of why inequalities exist. Finally, the concluding step in Arksey and O'Malley's original structure for scoping reviews includes a discussion with stakeholders of the findings [75]. This has not been formally undertaken with external stakeholders, but was addressed internally by the review team which included both researchers and clinicians. A recent scoping review on the conduct and reporting of scoping reviews suggests relatively few published scoping reviews undertake this step [76].

CONCLUSION

This scoping review was essential to benchmark the current evidence base and to demonstrate the paucity of published studies to date for this population. It has identified that inequalities exist throughout the prevention, care and support pathway for adults with MS, but the interpretation of these findings are limited by the lack of consistency between studies and across different types of care or support. In part, this may be because inequality is likely to be context specific and, in part, because of the limitations of the study design. There were also some specific research gaps identified, particularly in relation to prevention, vocational support and patient information and within inequality groups, learning disabilities and other 'vulnerable' groups. Inequalities or disparities in access to all levels of services and treatments will need to be addressed through a strategic research agenda. Further research to explore these areas requires large-scale population-based databases to ensure that participants are representative. Longitudinal studies also need to be responsive to changes in evidence about the management and treatment of MS. Further research is needed into understanding the reasons for differences in access to develop strategies to address any inequality. The findings of this scoping review will help to inform the prioritisation of future research for this population internationally.

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